



S. 1382 – ALS Registry Act

FLOOR SITUATION

S. 1382 is being considered on the floor under suspension of the rules and will require a two-thirds majority vote for passage. This legislation was introduced by Senator Harry Reid (D-NV) on May 14, 2007. The Senate passed the bill on September 23, 2008, by unanimous consent. The House passed its version of the bill, H.R. 2995, on October 16, 2007, by a vote of 411-3.

S. 1382 is expected to be considered on the floor of the House on September 25, 2008.

SUMMARY

S. 1382 directs Centers for Disease Control and Prevention (CDC) to develop a system to collect data on Amyotrophic Lateral Sclerosis (ALS) and establish a national registry for the data. CDC must then establish a National ALS Registry for the collection and storage of such data.

The bill provides that within 18 months of the enactment, the Health and Human Services Department may report to Congress with registries under development, planned registries, the criteria involved in determining what registries to conduct, defer, or suspend, and the scope of those registries.

BACKGROUND

Amyotrophic Lateral Sclerosis (ALS) is a progressive, neurodegenerative disease which is usually fatal. The disease affects motor nerve cells in the brain and spinal cord. The cause of ALS is not well understood, and there is no known cure for the disease. More than 5,000 individuals in the United States are diagnosed with ALS each year. Notable people affected by ALS include Stephen Hawking, Lou Gehrig, and Jacob Javits.

ALS is one of the most common neuromuscular diseases worldwide, and it affects men at a slightly higher rate than women. According to the ALS Association, military veterans have a higher chance of contracting ALS, especially Gulf War veterans.

COST

The Congressional Budget Office (CBO) has not produced a cost estimate for S. 1382 as of September 24, 2008.

STAFF CONTACT

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